

Angels at Bethesda

Charitable medical air transportation serving patients of the National Institutes of Health

Pilot Says Usher's Patient Was 'All Grins'

Heather K. needed a smooth landing. The petite 19-year-old from Heyworth, Ill., suffers from Usher syn-

quick to point out the exclamation was due, not to a hard landing, but "a very smooth" one, as Heather said in sign language. "She was all grins," notes Clawson.

Heather graduated from University High School this year and is enrolled at Heartland Community College where she will study art and pursue an associate's degree.

"They found Usher's last year through a routine eye exam," says Michelle, her mother. "The doctor saw something on her retina. Since she was 10 or 11, it's been difficult for her to see."

Of the disorder's three types, Heather has Type 1, characterized by deafness from birth, problems with balance, and eventual loss of vision.

There is no cure for Usher's, but scientists hope to identify the genes causing the symptoms and define their function.

The disease, transmitted through both parents, affects about four babies in every 100,000 births, according to



Heather (2nd from left) and family pose with Clawson (far left) and his Piper Archer

the National Institute on Deafness and Other Communication Disorders at NIH.

At the institute, doctors performed DNA and other tests. "They did tons of tests on her eyes—nine hours' worth," her mom says. Heather has no night or peripheral vision.

She has three brothers, Joshua, Jonathan, and Jason. "We all sign in the family," explains Michelle. This includes Heather's father, Bert.

Pilot Clawson says Heather, whose mother accompanied her and who had never flown before, remained "glued to the window" during the flight. "I loved flying them. They are very, very appreciative of Angel Flight."



Heather and boyfriend Ian pause for a photo before leaving for prom

drome, a rare genetic disease that caused her to be born profoundly deaf and gradually to lose her vision due to RP, or retinitis pigmentosa.

Angel Flight flew her to NIH in July to participate in a research study. "She let out a squeal when we landed," says pilot Ben Clawson. But he was



Kentucky Woman Shines Despite Vision Loss

The medical name is complicated: “Familial exudative vitreoretinopathy.” Mostly it’s known as FEVR, a genetic progressive eye disease caused by a defective gene.

Vicki S., 50, of Madison, Ky., has FEVR and is blind in her left eye and lacks central vision in her right. But the disorder doesn’t interfere with her thriving musical career.

The bluegrass band member is a vocalist, song writer and bass guitarist for Coon Creek, a band led by the highly-acclaimed singer, Dale Ann Bradley (www.daleann.com).

Angel Flight flew Vicki and her brother to NIH in June to participate in a clinical study of the National Eye Institute, designed to identify genes responsible for the disorder.

FEVR affects blood vessels in the eyes and can lead to retinal detachment and vitreous bleeding, causing critical vision loss and even blindness. (The vitreous is the clear, jelly-

like substance that fills the middle of the eye and gives it shape.)

Vicki, who developed vision problems when she was around 10, had lost total sight in her left eye by the

annual Podunk Bluegrass Festival in East Hartford, Conn., where the band is a popular feature each year.

Vicki was diagnosed with FEVR “six or seven years ago. I never have driven. I went to college. The biggest challenge was reading. I went to audio books and speech programs on computers. I use my ears.”

As for her experience with her two-legged Angel Flight, she said she has flown a lot, “but not in small planes. The pilots were nice and very efficient. It’s a very generous thing for them to do.”



Angel Flight Patient Checklist

- Must be able to get into plane
- Can sit upright during flight
- Requires no medical treatment or special apparatus such as vent, feeding tube, IV, etc. (Oxygen is allowed.)
- Traveling to a destination not exceeding 1,000 miles
 - Has financial need
- Receives clearance from physician
- Observes weight restrictions

age of 12.

Her interest in music came early. As a child, “I was playing piano and reading music. I bought a guitar and began playing in a band in 1979.” The New Coon Creek Girls of Renfro, Ky., was a resurrection of the original Coon Creek Girls string band that had performed in the White House in 1939 for President and Mrs. Roosevelt.

Vicki recently returned from the



NIH Missions January 2004 to July 2005

Missions	103
Passengers	97
Patients	61

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Ed Boyer

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Flight program at www.americawest.com. Click “My AWA,” then “Donate Miles,” then Angel Flight.

If you have Delta Airline miles to donate, go to <http://www.delta.com/search/index.jsp> and give through the United Way program listed there as one of the charities operated for patient families by Angel Flight.

Everybody helping a little can mean free flights for patients and their families.

Ed Boyer is the CEO and president of Angel Flight of Virginia, and winner of the 2005 Lifetime Achievement Award of the Virginia Department of Aviation.